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# Sexual Health and Spinal Cord Injury

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# Sexual Health and Spinal Cord Injury

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Occupational Therapy

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# Sexual Health and Spinal Cord Injury

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## **CLINICAL SCENARIO:**

Sexual health and intimacy rank very high in level of importance and quality of life for people with a spinal cord injury (SCI). It is also stated in many research findings that improving sexual function remains a priority for people with SCI. Even though this is important, it isn't reflected in the education and care received by people with SCI about sexual health. This is a multi-level issue, which includes people with SCI and health care providers, and their feelings and attitudes about sexual health and intimacy. Before talking to clients about sexual health, the provider needs to be comfortable with him or herself as a sexual being and the provider needs to feel open about starting a conversation and talking about sexual health with a client (Tepper, 1997). This includes feeling comfortable talking with someone that has differing opinions or different sexual orientation.

Occupational therapists (OT) have the unique education and philosophy of practice to take the research and information provided and incorporate it into OT practice service on a holistic scale.

## **FOCUSSED CLINICAL QUESTION:**

**What is the role of occupational therapist when working with people with spinal cord injury and sexual health?**

## **SUMMARY of Search, 'Best' Evidence appraised, and Key Findings:**

- A total of five articles investigating sexual health and people with a spinal cord injury were analysed for this CAT. The systematic review by Abramson et al. (2008) was chosen as "best" evidence.
- This systematic review looked at all questionnaires between 1986 and 2006 given to people with SCI and their families. For this review, the only surveys used were questions specifically for the person with SCI, focusing on sexual function, interest and satisfaction. Four outcome measures were reviewed and results were divided into four tables.
- Results of the systematic review stated the importance of using quantitative and qualitative measures when interviewing a client. The use of these measures may also help to initiate the conversation and present to the client

a willingness to discuss sexual concerns. One limitation noted was the language used in the measures was biased toward people in heterosexual relationships.

- Anderson et al. (2008) surveyed people with SCI about sexual health and concerns. The survey could be completed on-line or paper pencil to encourage people who may not feel comfortable talking to someone about their sexual activities. Questions included; limitations to sexual activity, adaptive equipment and medication used, and bowel, bladder and autonomic dysreflexia (AD) concerns.
- Tepper (1997) published an article on his weekend workshop with health care providers. This workshop explored insecurities, provided awareness and offered new ways of working with people with spinal cord injuries and sexual health. Surveys with questions about comfort levels and education about sexuality and SCI were given before, immediately after, and 5 months after the workshop.
- Burch (2008) preformed an one-hour training for health care professionals working with people with SCI in a rehabilitative setting. The focus of this training was to educate HCP about working with people with varying sexual orientation. It was a cross-sectional study, comparing the knowledge and overall feeling of different professionals.
- Bastanfer and Crewe (2005) administrated a qualitative interview to five men with spinal cord injuries about how their life has changed since their accident. This interview included; identity, satisfaction, love life, intimacy, and barrier to sexual health.

### **CLINICAL BOTTOM LINE:**

Sexual activity is an activity of daily living. Overwhelming research finds that intimacy and sexual health is very important when clients are asked about quality of life. Education and training for practitioners is necessary to increase knowledge and comfort talking about sexual issues with clients and their families. This includes talking with patients whose sexual orientation may be different then the therapist. Current surveys and measures can help initiate the conversation between the OT and the clients.

### **Limitation of this CAT:**

This CAT has not been peer reviewed. An exhaustive literature search was not conducted on this topic. Also, the writer is not an expert on this topic; the CAT was completed as part of a class project.

## SEARCH STRATEGY:

### Terms used to guide Search Strategy:

- Patient/Client Group: Occupational Therapist providing SCI rehab
- Intervention (or Assessment): Education / level of confidence/ practical use of new information
- Comparison: Null
- Outcome(s): Ideas for future research projects, interventions and continuing education for therapist.

Date	Databases and sites searched	Search Terms	Number of Articles	Limits Used
9/10	Medline	SCI and sexual function SCI and sexual intimacy OT and SCI SCI and Quality of Life	<ul style="list-style-type: none"><li>• 36</li><li>• 1</li><li>• 30</li><li>• 445</li></ul>	English
10/10	CINHAL	SCI and sexual function SCI and sexual intimacy Rehab and SCI	<ul style="list-style-type: none"><li>• 46 / 5 repeats</li><li>• 0</li><li>• 18</li></ul>	English Full text only
10/10	OT Search	SCI and sexual function SCI and sexual intimacy	<ul style="list-style-type: none"><li>• 2/ 2 repeats</li><li>• 0</li></ul>	No limits used

## INCLUSION and EXCLUSION CRITERIA

### Inclusion:

- People with spinal cord injury,
- Health care providers, specifically occupational therapists, that work in spinal cord injury rehabilitation centers,
- Articles relating to sexual intimacy, function and satisfaction
- English

### Exclusion:

- Articles about other ADLs and spinal cord injury
- Spouses and partners of people with spinal cord injury
- People under 18 years old.
- Articles written in a language other than English

## RESULTS OF SEARCH

**Table 1:** Summary of Study Designs of Articles retrieved. Five relevant studies were located and categorised as shown in Table 1 (based on Levels of Evidence, Centre for Evidence Based Medicine, 1998)

Study Design/ Methodology of Articles Retrieved	Level	Number Located	Author (Year)
<b>Cross-sectional</b>	<b>IV</b>  <b>III</b>	<b>2</b>	Anderson, K.D., Borisoff, J.F., Johnson, R.D., Stiens, S.A., Elliott, S.L. (2008) The impact of spinal cord injury on sexual function: concerns of the general population. Spinal Cord. 45 p.328-337  Burch, A. (2008) Health care providers' knowledge, attitudes, and self-efficacy for working with patients with spinal cord injury who have diverse sexual orientation. Phys Ther. 88 p.191-198
<b>Systematic review</b>	<b>II</b>	<b>1</b>	Abramson, CE; McBride, KE; Konnyu, KJ; Elliott, SL and the SCIRE Research Team. (2008) Sexual health outcome measures for individuals with a spinal cord injury: a systematic review. Spinal Cord. 46 p.320-324
<b>Before and after</b>	<b>III</b>	<b>1</b>	Tepper, M.S.(1997) Providing comprehensive sexual health care in spinal cord injury rehabilitation: implementation and evaluation of a new curriculum for health care professionals. Sexuality and Disability (15) 3. P.131-165.
<b>Qualitative</b>	<b>NA</b>	<b>1</b>	Bastanfer, R.B; Crewe, N. (2005) A Qualitative study of the dating behaviours of men with a spinal cord injury. SCI Psychosocial Process (18) 2. p.76-82

## BEST EVIDENCE

The following study/paper was identified as the 'best' evidence and selected for critical appraisal. Reasons for selecting this study were:

Abramson, CE; McBride, KE; Konnyu, KJ; Elliott, SL and the SCIRE Research Team; Sexual health outcome measures for individuals with a spinal cord injury: a systematic review (2008) Spinal Cord (46) 320-324

### **Reasons**

- This systematic review looked through relevant measures since 1986 and confined the study to four measures that were specifically designed for people with SCI and their sexual health. The authors clearly stated the limitations and concerns about how the health profession is treating people with SCI and sexual health. It also explains how these measures can be used to initiate a conversation about sexual health with a client.
- The article is concise, an occupational therapist could read it and understand what measures to use, why they are important and understand the limitation that included.

### **SUMMARY OF BEST EVIDENCE**

Sexual health outcome measures for individuals with a spinal cord injury: a systematic review. By: Abramson, CE; McBride, KE; Konnyu, KJ; Elliott, SL and the SCIRE Research Team; (2008)

#### **Aim/Objective of the Study/Systematic Review:**

This systematic review evaluated questionnaires for people with SCI about sexual function and interest and their satisfaction with both. It also looked at how relevant these tools are when working with people with SCI and made recommendations for future questionnaires

#### **Study Design:**

Systematic review

#### **Methods and Search Strategy:**

This review was part of a more inclusive study investigating all questionnaires given to people with SCI and their families. Electronic databases were used to find surveys and measures published between 1986 and 2006. All measures accepted for this review included published psychometric properties with reliability, validity and responsiveness coefficients in their reports. The procedures for this systematic review included finding questionnaires regarding sexual health specifically addressing people with SCI. The psychometric properties of the measures reviewed were compared in four tables in the systematic review.

#### **Selection Criteria:**

Studies were selected base on these criteria:

- Limited to people with SCI
- Specifically asked about sexual function, interest and satisfaction

- Included psychometric properties with reliability, validity and responsiveness coefficients in their reports.

**Setting:**

- There was no limitation to setting.

**Participants:**

- People with SCI in United States and Canada

**Intervention Investigated:**

- No intervention preformed

**Control: null**

**Experimental: null**

**Outcome Measures:** as in table below.

- A health care practitioner (HCP) administers all scales below it to a person with SCI.
- The Emotional Quality of the Relationship Scale is a self-report tool to collect information from people with SCI that are in relationships. It measures feelings of affection and intimacy, problem solving and communication. This is a good scale to use in conjunction with a qualitative measure.
- Sexual Activity and Satisfaction Scale is an interview style measure that asks questions about sexual desire, activity and satisfaction. This is a good scale to use to initiate a conversation about issue around sexuality.
- Sexual Attitude and Information Questionnaire evaluates the effectiveness of counselling and sexual education classes for people with SCI. It consists of four scales and one overall item: sexual information, sexual behaviour acceptability, sexual concerns and non-sexual information and an over-all rating. This was originally published in 1980 so it may need to be updated.
- Sexual Interest and Satisfaction Scale looks at the adjustment after SCI. It includes questions about pre and post behaviours and may be good at initiating conversations about sensitive topics.



## Outcome Measurement Characteristics

Outcome Measure	Construct Measured	Items and response scale
Emotional Quality of the Relationship Scale (EQR)	- Emotional intimacy - Affection - Communication	7 items on a 4 point rating scale
Sexual Attitude and Information Questionnaire (SAIQ)	- Sexual information - Sexual behavior acceptability - Sexual concerns - Non-sexual concerns	38 items on a 6 point rating scale
Sexual Activity and Satisfaction Scale (SAS)	- Sexual activity - Sexual Satisfaction	3 items of varies point rating scales
Sexual Interest and Satisfaction Scale (SIS)	- Sexual adjustment (sexuality and sexual adjustment)	7 items on a 4 point rating scale

Table adapted from: Abramson, CE; et al. (2008) Sexual health outcome measures for individuals with a spinal cord injury: a systematic review. *Spinal Cord*, 46, 322. (Original table © 2008, International Spinal Cord Society)

## Main Findings:

### Original Authors' Conclusions

Over the last twenty years, only four surveys have been designed to interview a person with SCI about sexual health. Currently, the International Index of Erectile Function (IIEF) and the Female Sexual Function Index (FSFI) are being used which are not even specific to people with SCI. Updated versions of the measures specifically for people with SCI need to be developed and include; questions about sexual priorities, bladder, bowel and AD issues, sexual orientation and partner status and functional ability to participate sexually.

## Critical Appraisal:

### Validity:

- The tables provided an easy to understand format.
- Table two provided reliability scores. ERQ was not measured for reliability. When measuring internal consistency the SAIQ used a split-half reliability twice and the r value was .68-.81 and .47-.90. This was the only measure that was retested, the r-value was .69-.91. The r-value of the SAS was .87 and .96 for the SIS.
- Table three provided validity scores. It showed the r-value of convergent/divergent/ known group validity. Some of the measures share scales and the validity can differ from one measure to another. One very large difference is the Hospital and Anxiety and Depression scale (HAD). Given in the ERQ measure  $r = -.38$  and in the SAS measure the HAD validity was  $r = .49$ .
- In table four, only the SAIQ was measured for responsiveness. The mean change in rating score was  $P < .05$  in both sexual behaviour acceptability and concern about sexual function in the pre and post-sexual education measure.
- Only one measure had scores for content validity and both r-values were negative numbers.

### Interpretation of Results:

- This systematic review explains what questionnaires and surveys are available for talking with clients with SCI. It is comprehensive in showing limitations and concerns about the different measures and at the same time it explores ways to combine different surveys together.
- Because there are mixed results on validity these surveys may be discounted. But it gives a good description of what is valid and possibly how to different questions can be put together to create a more inclusion measure.
- In the systematic review, it is stated the data was analysed separately and this could have an impact on the results and the validity.
- Table two indicated both SAQ and the SAS used split-level reliability is a weaker form of reliability.

### Summary/Conclusion:

- This is a good place for a therapist to start when looking for information about working with people with SCI. The systematic review gives a good general review of measures and also offers ideas on limitations what how future surveys can include. Talking with clients about sexual health is a very personal topic and the questions on these surveys give a good opening to having that conversation. Also, because it is a very personal issue, quantitative studies would not capture the depth and important details that are needed in understanding sexual health.

### Summary of articles from Table 1:

Author	Summary
Anderson et al. (2008)	<p><b>Purpose:</b> The main purpose was to gain a better understanding on how the general population of people with SCI felt about their sexual function.</p> <p><b>Method:</b> Information and flyers were posted on popular SCI websites. Adults with SCI, obtained a pass code for a web-based survey, accessed the anonymous survey, completed the questionnaire.</p> <p><b>Intervention:</b> No intervention implemented in this study.</p> <p><b>Outcomes:</b> Information was presented in graph format. Graphs included; secondary health issues of participants, types of medication, primary reason for pursuing sexual activity, and physical conditions experienced during sexual activity.</p> <p><b>Results:</b></p> <ul style="list-style-type: none"><li>• Majority of people with SCI state their sexual function has been altered since their accident.</li><li>• Physical conditions, like bladder, bowel and AD concerns, only limit a</li></ul>

	<p>small population of pursuing sexual activities, but it is a significant issue.</p> <ul style="list-style-type: none"> <li>• The majority of participants also stated improving their sexual function would increase their quality of life.</li> <li>• Intimacy is the overwhelming reason people participate in sexual activity.</li> </ul>
Burch (2008)	<p><b>Purpose:</b> The purpose of this training was to look at the attitude, knowledge and self-efficacy of HCP working with people with SCI and is gay, lesbian, bisexual or transgender (GLBT).</p> <p><b>Method:</b> Rehabilitation facilities were randomly selected by a national computer generated list. An e-mail explaining the project was sent out, and if the facility was interested they contacted the trainer and a time was set for the training. Seven facilities participated.</p> <p><b>Intervention:</b> The intervention is a videotape shown to HCP to increase self-efficacy when working with people in the GLBT community. A pre and post survey was given to the participants about comfort level and knowledge about patient who are GLBT.</p> <p><b>Outcomes:</b> Areas of outcomes included; stage of change in thinking about diversity in sexual orientation, HCP level of knowledge of and attitude toward patients who are GLBT, and self- efficacy for providing services to GLBT patients.</p> <p><b>Results:</b></p> <ul style="list-style-type: none"> <li>• Of the 402 participants, 93 were occupational therapist.</li> <li>• Of all the participants, 79% had never thought about diversity in sexual orientation before the training.</li> <li>• 44% of nurses had full respect for this population. This was higher then all other HPC combine. Only 387 answered this question.</li> <li>• 78.9% “strongly agreed” the training improved their self-efficacy in regards to sexual orientation diversity.</li> </ul>
Tepper (1997)	<p><b>Purpose:</b> A three-day workshop for HCP to implement new sexual health curriculum at rehabilitation centers. Also, the workshop was designed to educate participants about working with people with SCI by providing knowledge and skills necessary to be an effective therapist.</p> <p><b>Method:</b> Enrollment was limited to 18 people because this was a pilot project and there were numerous interactive activities. Participants all worked in a rehabilitative facility for at least 50 % of their time. In addition to the participants, seven people with SCI were trained to present certain conditions and specific sexual problems to the therapists. They also helped teach and give feedback to the therapists during activities.</p> <p><b>Intervention:</b></p>

	<p>The workshop started with a pre-test inquiring about comfort and skill level working with people with SCI. Education about the PLISSIT therapy model (permission, limited information, specific suggestion, and intensive therapy) was incorporated throughout the entire weekend, specifically the first three steps. There was also role-playing activities. To evaluate how much they learned from the weekend workshop, there was a follow up questionnaire at the end of the weekend. Each participant agreed to provide an in-service to their co-workers about what they learned within five months. At that time, each participant was also sent another survey.</p> <p>Outcomes: The pre and post questionnaires provided information comfort, knowledge and skill level in health care providers working with sexual health and people with SCI. Also, the five-month survey provided information about what is being implemented into daily practice.</p> <p>Results:</p> <ul style="list-style-type: none"> <li>• There was an overall improvement in knowledge regarding sexual function and SCI.</li> <li>• Information was shared with co-workers, either formally or informally.</li> <li>• When asked, about half to three-quarters of clients agreed to participate in a sexuality assessment.</li> <li>• There was not a difference between medical and nonmedical providers in answers about comfort, knowledge and skill level about sexual health and SCI.</li> </ul>
<p>Bastanfer, R.B; Crewe, N (2005)</p>	<p>Purpose: This study aims to describe the social and sexual behaviour of males with SCI.</p> <p>Method: This study took place at a university. All eligible people on campus were contacted by phone or e-mail. All participants needed to be male and have a SCI severe enough to be in a wheelchair. Questions for the interview were taken from a larger questionnaire written by Howland and Rintala. Each participant was encouraged to add as much information as they wanted to their answers. The data was analysed to formulate common themes.</p> <p>Intervention: There was no intervention for this study.</p> <p>Outcomes: This qualitative study provided comparisons between different men with SCI and their feelings about sexual health. It provided an in depth look at the varying opinions and personalities of people with SCI.</p> <p>Results:</p> <ul style="list-style-type: none"> <li>• Eight common domains were identified and described in detail.</li> <li>• SCI is a meaningful change in life and identity.</li> </ul>

	<ul style="list-style-type: none"> <li>• Dissatisfaction with love-life</li> <li>• Intimacy as a form of function of agency</li> <li>• Societal and sexual bias as barrier to intimacy</li> <li>• Expression and need for intimacy</li> <li>• Diminished sexual functioning</li> <li>• Coping with lack of intimacy</li> <li>• No masturbation</li> </ul>
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## **IMPLICATIONS FOR PRACTICE, EDUCATION and FUTURE RESEARCH**

### **Practice**

In practice, it is important for occupational therapist to be comfortable with themselves as a sexual being in order to truly help someone else work towards sexual health. Sexual health is very important to most everybody and this includes people with SCI. One study showed that approx 89% of the SCI population surveyed were sexually active before their accident and 87% were sexually active after their accident. This gives a very simple but very important message, people with SCI are most likely sexually active.

Also, the PLISSIT Model (permission, limited information, specific suggestions, intensive therapy) was only mentioned in study but seems like it is a good straightforward philosophy for occupational therapists to implement into their practice. (Tepper, 1997)

### **Education**

Education is important on two levels, one is education given to providers by experts. In a few different studies, participants stated they felt much more confident about talking to people about sexual function and intimacy after they attended an educational workshop. Educating providers could either happen in the classroom or throughout one's career. The other element of education is the information that the providers give to their patients and how they present it. Like stated earlier, it is very important the provider feels comfortable with themselves and about talking about it before they can be helpful to others.

### **Research**

There is very little research being done on how to improve sexual health for people with SCI. And the research that is being done usually only includes heterosexuals in a committed relationship. To continue the work that has been

done, it would be easy to take the surveys that have been developed and update them, modify them for a diverse population of sexual orientation and use different mediums to gather information.

Surveys have been given to people with SCI to provide greater information on how they feel about intimacy, sexual function and related issues. Health care providers have participated in workshops and weekend long conferences to improve understanding and familiarity in working with people with SCI. All of these projects have made it clear that more education, understanding and acceptance are still needed.

## REFERENCES

Abramson, CE; McBride, KE; Konnyu, KJ; Elliott, SL and the SCIRE Research Team. (2008) Sexual health outcome measures for individuals with a spinal cord injury: a systematic review. *Spinal Cord*, 46, 320-324.

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